



General Assembly

January Session, 2011

**Committee Bill No. 543**

LCO No. 3307

\*03307SB00543PH\_\*

Referred to Committee on Public Health

Introduced by:  
(PH)

**AN ACT PROVIDING NEWBORN SCREENING FOR SEVERE  
COMBINED IMMUNODEFICIENCY DISEASE.**

Be it enacted by the Senate and House of Representatives in General Assembly convened:

1 Section 1. Section 19a-55 of the general statutes is repealed and the  
2 following is substituted in lieu thereof (*Effective October 1, 2011*):

3 (a) The administrative officer or other person in charge of each  
4 institution caring for newborn infants shall cause to have administered  
5 to every such infant in its care an HIV-related test, as defined in section  
6 19a-581, a test for phenylketonuria and other metabolic diseases,  
7 hypothyroidism, galactosemia, sickle cell disease, maple syrup urine  
8 disease, homocystinuria, biotinidase deficiency, congenital adrenal  
9 hyperplasia and such other tests for inborn errors of metabolism as  
10 shall be prescribed by the Department of Public Health. The tests shall  
11 be administered as soon after birth as is medically appropriate. If the  
12 mother has had an HIV-related test pursuant to section 19a-90 or 19a-  
13 593, the person responsible for testing under this section may omit an  
14 HIV-related test. The Commissioner of Public Health shall (1)  
15 administer the newborn screening program, (2) direct persons  
16 identified through the screening program to appropriate specialty

17 centers for treatments, consistent with any applicable confidentiality  
 18 requirements, and (3) set the fees to be charged to institutions to cover  
 19 all expenses of the comprehensive screening program including  
 20 testing, tracking and treatment. The fees to be charged pursuant to  
 21 subdivision (3) of this subsection shall be set at a minimum of fifty-six  
 22 dollars. [The commissioner shall adopt regulations, in accordance with  
 23 chapter 54, to implement the provisions of this section.] The  
 24 Commissioner of Public Health shall publish a list of all the abnormal  
 25 conditions for which the department screens newborns under the  
 26 newborn screening program, which shall include screening for amino  
 27 acid disorders, organic acid disorders and fatty acid oxidation  
 28 disorders, including, but not limited to, long-chain 3-hydroxyacyl CoA  
 29 dehydrogenase (L-CHAD) and medium-chain acyl-CoA  
 30 dehydrogenase (MCAD).

31 (b) In addition to the testing requirements prescribed in subsection  
 32 (a) of this section, the administrative officer or other person in charge  
 33 of each institution caring for newborn infants shall cause to have  
 34 administered to every such infant in its care a screening test for cystic  
 35 fibrosis and a screening test for severe combined immunodeficiency  
 36 disease. Such screening [test] tests shall be administered as soon after  
 37 birth as is medically appropriate.

38 (c) The provisions of this section shall not apply to any infant whose  
 39 parents object to the test or treatment as being in conflict with their  
 40 religious tenets and practice. The commissioner shall adopt  
 41 regulations, in accordance with the provisions of chapter 54, to  
 42 implement the provisions of this section.

This act shall take effect as follows and shall amend the following sections:

Section 1	<i>October 1, 2011</i>	19a-55
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**Statement of Purpose:**

To provide newborn screening for severe combined immunodeficiency disease.

*[Proposed deletions are enclosed in brackets. Proposed additions are indicated by underline, except that when the entire text of a bill or resolution or a section of a bill or resolution is new, it is not underlined.]*

Co-Sponsors: SEN. MCKINNEY, 28th Dist.

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